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**Full title: “*It’s about willpower in the end. You’ve got to keep going*”: a qualitative study
exploring the experience of pain in inflammatory bowel disease**

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Abstract

Background: Pain is a widely experienced symptom of inflammatory bowel disease (IBD), which has significant psychological and functional impacts on patients. Understanding the aetiology and

management of chronic pain is a poorly understood area of IBD research. This qualitative study aimed to explore the experiences of individuals with IBD and pain, the pain management strategies they use and any needs for future pain management interventions.

Methods: Fourteen individuals with IBD were purposively recruited and interviewed (face-to-face or telephone) using a topic guide. Interviews were transcribed and analysed using inductive thematic analysis.

Results: Themes identified were ‘vicious cycles’, ‘findings solutions’ and ‘attitudes’. The experience and impact of pain were rarely viewed in isolation, but rather within the context of a cycle of IBD symptoms. Other ‘vicious cycles’ identified included anxiety, avoidance and inactivity and poor understanding and communication. Pain management included short and long-term strategies.

Searching for a solution for pain had an emotional impact on individuals. There were contrasting attitudes from participants, including defeat, tolerance and acceptance.

Conclusions: This study provides an understanding of the experience of pain in IBD. The interaction of pain with accompanying IBD symptoms has an emotional and physical impact on individuals, and creates a barrier to adequate assessment, understanding and treatment of pain. Patients rely on their own experiences and a trial and error approach to apply helpful strategies. Adjuvant behavioural therapies may be beneficial for patients experiencing pain and psychological distress, and to facilitate self-management.

Key words: Inflammatory Bowel Disease, Pain, Qualitative Study, Thematic Analysis

Introduction

Inflammatory bowel disease (IBD) is a chronic gastrointestinal disease with a relapsing and unpredictable prognosis. It affects between one in 200 and one in 300 people in high-income countries and has rising incidence rates in low and middle-income countries (1-3). IBD is mostly comprised of Crohn’s disease (CD), where inflammation can occur anywhere from the mouth to the anus, and ulcerative colitis (UC), affecting the colon only. Symptoms of IBD include weight loss, diarrhoea, fatigue and abdominal pain, which result in a low quality of life and symptom burden for patients.

Developing a thorough understanding and optimising management of IBD symptoms, predominantly pain and fatigue, were among the top 10 questions raised in a research priority setting by patients and clinicians (4). Pain is experienced by up to 70% of patients in active disease and 20-50% of patients in remission (5). In active disease, bowel dysmotility and disease-related complications such as strictures, adhesions and fistulas are among contributing factors (6, 7). However, joint pain has also widely been reported by patients (8). The aetiology of chronic pain is a poorly understood area of IBD, with research to date addressing visceral hypersensitivity, dysregulated central and peripheral pain signalling and psychological factors as important areas for investigation (5).

With a current limited understanding of pain in IBD, treatment approaches to pain management in IBD is a similarly unresearched area. In periods of active disease, optimising IBD medical therapy, and if necessary, surgery, are used to alleviate pain symptoms and underlying exacerbating factors such as inflammation. However, use of these approaches in remission is invasive, distressing and can put patients at further risk of complications. Norton et al.'s (9) systematic review reinforced the heterogeneity in approaches for pain management in IBD, including a range of pharmacological (e.g. antibiotics, nicotine patches, cannabis), dietary (e.g. low FODMAP diet) and psychological approaches. Promising results were found for psychological approaches, such as disease-specific cognitive behavioural therapy (CBT) (10), stress management (11) and cognitive skills training (12). However methodological shortfalls and small samples sizes limited conclusions in this area.

It is recognised that pain in IBD is a biopsychosocial construct (5). A recent systematic review by Sweeney et al. (13) identified that a range of clinical factors and both negative and positive psychosocial factors were associated with pain in IBD. Depression, anxiety, stress and pain catastrophising were among negative psychosocial factors associated with greater pain severity and pain-related interference. Conversely, active coping, perceived social support and an internal locus of control was associated with less pain. The majority of included studies were of cross-sectional design which limited causative inferences, however the review suggests that psychosocial factors may play an important role in pain in individuals with IBD.

To develop a better understanding of IBD pain and facilitate the development of effective interventions, further research is required. This includes gaining a better insight into patient's experiences of pain, their understanding of pain in IBD and current strategies used to manage this burdensome symptom. Moreover, for the development of effective interventions, research is required to gain a better insight into the needs of patients. The informative role of qualitative research is evident in intervention development for HIV-related chronic pain (14) and cancer-related fatigue (15). In IBD, one qualitative study explored pain in hospitalised patients (16). This revealed the frustration and perceived stigma felt by patients with IBD experiencing pain. However, no qualitative studies have explored the experiences of pain in IBD outside a hospitalised context. Therefore, the aim of this qualitative study is to gain a better understanding of i) the experience of pain in IBD ii) individuals' current management strategies for pain iii) the needs and preferences of individuals with IBD for future pain management interventions.

Methods

Design

A qualitative study using in-depth semi-structured interviews. A purposive sampling technique of maximum variation (17) was used to capture participants with a range of clinical and demographic backgrounds, who were all experiencing pain related to their IBD. Ethical approval for the study was obtained from London-Surrey Borders Ethics Committee (17/LO/1527).

Participants

Eligibility criteria included: i) a clinician-confirmed diagnosis of CD or UC ii) diagnosed for a minimum of six months iii) over 16 years of age iv) ability to read and write English v) experienced pain related to their IBD.

Procedure

Participants for this study were purposively selected from a database of patients recruited from three National Health Service outpatient gastroenterology clinics and took part in a cross-sectional survey on pain in IBD. Those who agreed to participate in further studies and met our eligibility criteria were contacted by email and invited to take part in this qualitative study. Seventeen patients were contacted by email, of which fourteen replied. Participants were given a choice of either face-to-face or telephone interview. Those who opted for the former provided written consent and those who opted for telephone interview provided verbal consent, as recorded within the interview. A semi-structured interview schedule was followed, of which questions and probes were developed and agreed by the research team and reviewed by patient public involvement members (Table 1).

Insert Table 1. Topic guide for IBD pain interviews

Individual one-off interviews were conducted by a female PhD student (LS) with experience in conducting interviews and leading a research project in IBD-pain. Field notes were taken during interviews and no other non-participants were present. There was no previous relationship between the participants and the researcher and participation had no impact on individual's clinical care. Interviews were audio-recorded and anonymised, and transcribed verbatim by a professional transcriber. Further participant invitations were stopped once no new themes were emerging from interviews, indicating that data saturation had been reached (18).

Analysis

Inductive Thematic Analysis using the Braun and Clarke method (19) was used to analyse interviews. Three authors (LS, LB & ZK) read through all transcripts and recordings were listened to repeatedly, to familiarise authors with the data and initiate generation of codes line by line. Transcripts were analysed using both paper and pen method and computer software NVivo Version 11, to allow codes

to be grouped into sub-themes and overarching themes. The research team met regularly to discuss, refine and agree on codes and themes, using diagrams and supporting quotes to facilitate decision-making and repeatedly re-read transcripts to ensure that codes, sub-themes and themes accurately reflected the data set.

Results

Fourteen individuals with IBD were interviewed, with interviews lasting between 30-60 minutes. This consisted of 8 females and 6 males, with age of participants ranging from 17 to 55 years. The sample was predominantly (64%) of White-British origin. Demographic and clinical details of interviewees are provided in Table 2.

Insert Table 2. Details of interviewed participants

Three key themes were identified from the data, ‘vicious cycles’, ‘findings solutions and ‘attitudes’, which were each split into further sub-themes (Figure 1). These are described in turn below with supporting quotes and participant number in brackets.

Insert Figure 1. Thematic map of pain in IBD

Theme 1. Vicious Cycles

Both the experience and impact of pain were described by participants amongst other IBD symptoms. There were a number of ‘vicious cycles’ identified within this context. Consequently, this theme is broken down into i) ‘cycle of IBD symptoms’ ii) ‘cycles of anxiety’ iii) ‘avoidance and inactivity iv) ‘poor understanding and communication’ and v) ‘breaking the cycle’.

- i) Cycle of IBD symptoms

Pain was often embedded within a cycle of accompanying IBD symptoms, most notably pain was frequently experienced with fatigue and feelings of urgency. For example, pain not only “*creates exhaustion*” (7) but also the feeling of being “*run down*” was also associated with “*a bit of a bad belly, a bit of discomfort*” (8).

Similarly, pain was frequently viewed as a warning signal of urgency:

“There’s a sense that the pain could be so much that you wouldn’t have control of your own bowel”
(6)

...as well as pain surrounding the passing of stools:

“[There is] pain associated with, after going to go the toilet. And in the lead-up as well, the lower bowel sort of cramp pain sort of tightness” (3).

Stemming from this recurrent cycle of symptoms, it was felt by participants that it was difficult to identify when they were experiencing a flare, and some would continue to experience symptoms in remission:

“I find it very difficult to identify a flare, because of my normal sort of low grade, bad bowels and pain and fatigue and bloating” (1).

The impact of pain was often linked with fatigue and/or urgency, particularly in relation to individual’s social and physical functioning. A fear of not being in control was a key barrier to enjoying social activities:

“My social life has really taken a blow because I’m a bit scared to do things in case the pain comes back and I’m not in my own safe environment” (14).

It was also felt that the combination of pain and recurrent urgency impacted participant's energy levels and functioning:

"You wake up with energy and you're like yes I'm ready to go, then you're in the bathroom or you're experiencing discomfort and you're exhausted. It's incredibly exhausting" (7).

Alongside the social and physical impact, pain and associated IBD symptoms affected individual's ability to work. Participants were worried about missing days off work due to sickness, poor performance whilst at work or perceived stigma from colleagues:

"At work you get the feeling that some colleagues might think that you are just malingering. You get a bit of paranoia" (3).

This in turn had an impact on participant's health:

"There seems to be this vicious cycle where the stress created from poor performance affecting my health and my health is affecting poor performance. And there seems to be no way out" (3).

Several participants had to stop working altogether or become self-employed to regain some control:

"I tend to shy away from work when [the pain is] particularly bad and just go back when I think I can cope with it" (10).

To help alleviate the stress caused by work and pain, one participant expressed their needs of wanting more information to be available about pain in the workplace:

“I think education for employers would be really helpful, about the impact of chronic pain has on people’s physical and mental health and their ability to work” (1).

A consequence of pain being entangled with other IBD symptoms resulted in participant’s feeling that pain was not addressed exclusively and did not take priority for healthcare professionals:

“it’s all about the bowel movements. It’s all about how often you go to the loo. And what you’re eating...I don’t think they focus on the pain so much.” (14).

ii) Cycles of Anxiety

Pain had an emotional impact on participants, who often expressed their distress and concern.

Experiencing pain was often perceived as a warning signal for either urgency or something serious related to their disease such as being *“worried my bowel was going to perforate” (12)*, which in turn created stress and anxiety, making participants feel more unwell or unable to cope. For one participant, *“...it’s the uncontrolled, uncertainty thing” (12)* that appears to be a key contributor in this anxiety:

“With the more acute pains, it makes me feel tense, it makes me tense up and then, and then my stomach tenses up and then it can get worse” (14).

Pain location, sensation and intensity varied considerably between participants, however it was noted that when pain was experienced in the abdominal region compared to other types of pain, this created the most anxiety for participants:

“...whenever [the stomach pain] happens, it’s a reminder of what could happen. I don’t get that with the joint pain so much, because it doesn’t feel like it’s related to the disease, even though it is,

because it's in my knee. And obviously, Crohn's is in the bowels. So even though it is related, it doesn't feel like it's related as such. It doesn't really kind of trigger those thoughts" (2).

iii) Inactivity and Avoidance

When experiencing symptoms, notably pain and fatigue, participants felt that this resulted in low motivation and energy to engage in activity:

When you've got low energy levels and your pain is worse you just want to sit there and not move and not do anything. And then things get worse and worse and worse" (5).

Participants recognised, however, that inactivity had a negative impact on mobility and overall health, which in turn made them feel less confident or able to engage in exercise. This negative feedback loop seemed to be a repeated occurrence:

"It does feedback – no exercise, poor health and poor health to do exercise. And back again" (3).

...and consequently impacted participant's perceptions of feeling enfeebled or "aged", "...like an eighty-year old" (13) and "it's almost as if I'm living in an older man's body" (3).

Despite this, participants recognised that exercise could be an effective strategy to help with pain and other symptoms, but the fatigue was a key barrier to achieving this:

"I've never really tried exercise. And yes, I don't know whether that would help or not. But I'd be willing to try. But with the fatigue, I find it really, really difficult to motivate myself to do any sort of regular exercise" (14).

iv) Communication and understanding

Participant's embarrassment and concealment of their symptoms appeared to clash with their frustration at a lack of understanding and awareness around IBD. This revealed a vicious cycle with regards to poor communication (to colleagues, peers, family) and a poor understanding of what participants were going through. Being aware of this lack of understanding made participants feel less likely to disclose what their pain was caused by, as they felt that they would need to explain their disease, which is *"something very intimate and personal and kind of embarrassing"* (6).

"I wouldn't really share the pain side of things, because I'd have to explain that was like the bigger picture" (2).

One participant shared that she had sought support through psychotherapy to help her communicate with her loved ones more effectively about her disease. A lack of understanding also transcended to participant's frustration at their own lack of understanding, and thus inability to effectively communicate what their pain felt like:

"...it's not like a stabbing pain, it's not like acid, I don't understand it. It's a new pain. Because I don't fully understand, I don't know how to explain it to anyone else" (6).

v) Breaking the Cycle

Participants were aware that they needed to break out of these vicious cycles to manage their pain in the long term, such as recognising the negative impact of prolonged periods of rest or inactivity.

Although having a *"safe environment"* (12) such as *"being at home"* felt *"more comfortable"* (14), it was also viewed as a *"trap"* (7).

In line with this, one participant said:

“It’s counterintuitive because when you’re sick, usually you’re supposed to relax and get better... You have to break that cycle. And you just have to go for a walk, you have to muster the energy to get up and do something” (5).

As well as motivating oneself to be active, another participant discussed breaking their cycles of angst that comes with pain... *“I think the moment the pain comes back, it makes me worry and I have to break that cycle” (12).*

Theme 2. Finding Solutions

The findings revealed the lack of a standardised approach to pain management in IBD. Participants relied on their own set of strategies, which they had adopted predominantly through learning from their own previous experiences through a ‘trial and error’ approach. These included a combination of both short-term strategies to relieve pain and long-term strategies to prevent pain onset and flaring of IBD symptoms. Many participants were still searching for solutions and looked for support or advice from their healthcare professionals, family or the IBD community. However, the act of searching itself had an emotional impact. The theme of ‘Finding Solutions’ is broken down into four sub-themes i) Learning through Experience ii) Short versus Long Term Strategies iii) Medication Concerns iv) Searching.

i) Learning through Experience

In finding the right solutions for managing their pain and IBD symptoms, it appeared that participants used their own set of strategies from personal experiences. Participant’s agreed that learning what worked for them through monitoring their symptoms over time was a useful way of finding their solutions:

“I think, with time, you definitely get to know your body and your pain better” (10).

For example, one participant recommended a grading approach to help manage the impact of diet and symptoms, which they utilised and had learnt over time:

“This is the traffic light system – green you can eat all the time, red just don’t touch it, it’s not going to be a pleasant result, yellow, from time to time you can dabble on these food, but don’t have too many too often” (5).

Conversely, two participants felt that they wanted to be told what to do to manage their pain and overall IBD *“that’s the one thing I would say would be helpful to manage it – actually have somebody to tell what do to” (8)* *“I need to know what I can take and can’t take” (12).*

ii) Short versus Long Term Strategies

Arising from previous experiences, it was apparent that the strategies used by participants fell into two main categories. Firstly, participants spoke of using short-term, immediate relief-type strategies. These included application of heat, physical or dietary soothing techniques, breathing/relaxation exercises, distracting oneself or being near the vicinity of a toilet:

“...teas, herbal teas, yoga, sometimes a hot water bottle. Loose fitting clothing” (7).

The extent to which participants drew from social support in times of pain varied between individuals. Some expressed great support and empathy from their loved ones:

“My husband, he’s amazing. He almost absorbs the pain for me sometimes” (7)

However, others shared that they preferred to cope alone:

“When I’m in pain, I just want to be completely alone and use the restroom” (6).

Long-term or maintenance strategies were also used by participants. These included taking a holistic approach to maintaining a healthy lifestyle, which was indirectly perceived to help with managing pain. A frequently discussed topic was around diet as a key maintenance solution to managing pain and flares. When pain was experienced in periods of remission, many participants attributed this to eating something they shouldn’t. However, there was significant heterogeneity in the types of dietary approaches for IBD pain management:

“When I realised I had too much dairy milk, it would hurt more” (7).

However, some participants struggled to find any dietary solution that worked for them:

“I get a bit confused with it because I think to myself I’m trying to like eat healthy and it still comes on. So, I don’t know what route to take” (3).

This confusion appeared to be exacerbated by the lack of consistent advice given from healthcare professionals *“the stoma nurses have a very different opinion to the dieticians” (13).*

Several participants identified that exercise or being active helped ease their pain:

“Staying active definitely helps me. But even if it’s just psychologically it definitely feels like it helps with the overall management of the disease.” (2).

However, this was not a uniformly agreed among all participants:

“Exercise makes it worse, yes. Definitely” (1).

Meditation was discussed by several participants, but the degree to which it was effective or helpful varied between individuals:

“A couple of years ago I introduced myself to meditation, because I felt like that – and I still think it’s really important” (7).

“I’ve looked into things like meditation. But it doesn’t really work for me” (3).

iii) Medication Concerns

Generally, participants were apprehensive about the long-term use of pain medication. Although some commented on how it was the only effective solution to keep their pain at bay, there were unwanted complications and side effects that came with taking it:

“Sometimes I end up having to take codeine, even though you’re not really supposed to - to mask the symptoms, but it does bung you up” (11).

“You can feel quite nauseous after a while, especially in the mornings after Tramadol” (3).

Moreover, it was viewed by one participant as the ‘last resort’ once they had exhausted their list of coping strategies:

“The only way I’ve found to be able to cope with those kinds of situation is that I’ve had to resort to taking pain relief because then at least I can get through” (10).

It was agreed among several participants that pain medication was not a sustainable solution in the long term, with one participant sharing their apprehension of becoming dependent on medication.

“I don’t want to become an addict” (13).

Others found that medication did not reduce their pain symptoms at all:

“I generally don’t use paracetamol or ibuprofen for the pain, because I don’t feel that they work for me” (9).

One participant shared their frustration at pain medication being their only offered solution:

“I’d really like someone to offer me an alternative to taking paracetamol constantly” (14).

iv) Searching

For other participants, it was evident that, despite having tried many strategies previously, they were still searching for a solution to their pain. One participant discussed how they were working with their healthcare professional on this continued search:

“I’m sure [my gastroenterologist] doesn’t know, I think he is good on patient-centred care, and together we’re trying to find a solution to how to make my pain better or go away” (1).

However, others felt dissatisfied with the lack of accessibility to their clinical team or the solutions offered to them. As a result, they were forced to look elsewhere for helpful solutions, such as IBD forums and close relatives with a clinical background:

“I don’t think I’ve been offered anything. A lot of it is me trying to find out what other people have tried” (10).

For some, this search was focused on finding ways to eliminate the pain completely, as the psychological and functional impact of pain was less tolerable than other symptoms:

“Making the pain go away is honestly the best thing for me. I would rather have the symptoms than have the pain, because the pain is just so frustrating that you can’t do a lot” (6).

For others, their search was focused on the need for psychological support to manage the disease, or feeling more equipped to cope or control the pain:

“For me, it's having a plan, having the pain under control, having routine appointments, always knowing that I have someone to talk to if it gets bad. And yes, addressing the anxiety issue that it brings as well” (7).

It was clear that there was an emotional impact and relentlessness to participant's search for a solution. A key barrier to finding an adequate solution for some was rooted in participant's and healthcare professionals lack of understanding of the causes of pain:

“Everyone keeps saying ‘oh it's IBS [Irritable Bowel Syndrome], it's just IBS. But I don't think it's just IBS because it's pretty constant and IBS can be managed by the medications that I take” (14).

This resulted in many participants feeling frustrated with the process and convey feelings of hopelessness:

“I feel kind of disheartened with other solutions, unless that means for sure, that is an evidence-based intervention that worked to get rid of people's pain completely” (1).

Several participants also expressed that surgery was their “big fear” (2) and that this would be a consequence of not being able to find a solution to their pain:

“I get a bit pessimistic about the pain never going away. And I worry a lot about the kind of the future ache in my colon. And recently I've started to worry a lot about having to get it taken out” (1).

Theme 3. Attitudes

The theme of ‘attitudes’ summarises the different approaches participants had towards their pain. As aforementioned, the act of searching for a solution led to individuals feeling hopeless and frustrated. Other attitudes taken by participants included tolerance, defeat and acceptance.

Participants had experienced pain so continually or frequently (*“mentally draining” (4) “unrelenting” (13)*) that they felt conditioned to a baseline level of some pain. This tolerance then became a barrier to effectively communicating pain in consultations:

“I just say it’s not that bad. And it’s become not that bad, because I deal with it on a daily basis” (6).

Participants reported that they frequently persisted with activities and daily demands, despite an awareness that their pain may be indicative of a flare. This ‘keep going’ attitude would be counterproductive at times, leading participants to feeling burnt out:

“The pain is telling me something’s not right and I need to rest, and then I push myself too far, I end up going more steps back than forward” (10).

Participants’ tolerance also reached a threshold for some, as they expressed getting to breaking point, when, for example pain became very severe or they were feeling stressed with daily demands:

“...if I get to the point where it’s a bit unbearable, I’ll go to the pub and just get to the point of I don’t care” (8).

Many participants expressed feeling defeated by their pain, particularly with regards to confidence and motivation to continuously cope with their pain. This stemmed from both the unrelenting nature of pain as well as participant’s feeling like they had exhausted all their possible solutions:

“Now I just feel like the pain has kind of beat me down” (1).

Part of this notion of feeling defeated included participants feeling like they had to succumb to *‘resorting to taking pain relief’* (10) as well as participant’s feeling like they had been defeated by the pain in both their social and work roles:

“It [pain] just slows you down massively and you’re trying to be the best mother you can be“ (13).

Conversely, others spoke of *‘being a fighter’* and *“not [having] the choice but to fight”* (13) or being from a stoic family who took an *“annoyingly hard”* approach (5). Aligning with this notion of battling with pain included efforts to control pain or using strong pain killers as *“weapons of choice”* (3).

On the other hand, some participants demonstrated a positive attitude, which was partly driven by having some level of acceptance of their pain, or by taking a different perspective. This acceptance appeared to have a positive effect on individual’s ability to cope:

“Once you start making peace with the pain, it’s almost like you have more control of it” (7).

A positive attitude also provided participants with motivation and resilience to implement the strategies they had previously found helpful:

“[It’s] kind of motivating! If you sit there you’re just going to get more pain and it’s just going to get worse. I think the more you walk, it’s almost like your body starts working” (5)

Other examples of the contrasting nature of these different approaches (tolerance versus acceptance) are presented in Table 3.

Insert Table 3. Example quotes of sub-themes of ‘Attitudes’ - Tolerance and Acceptance

Discussion

This is the first qualitative study to explore pain in IBD in a non-hospitalised context and has provided an insight into the experiences and impact of pain on individuals with IBD. The study highlights that

the experience and impact of pain are rarely viewed in isolation but rather are embedded within the overall experience of IBD symptoms, mainly pain's interaction with fatigue and urgency. Patients described this cycle as having a significant impact on emotional and physical functioning and acting as a key barrier to effective communication and management of pain. The breadth of strategies used among participants reinforces the lack of a clear consensus around optimal pain management in IBD, as supported by prior research finding a wide variety of interventions for abdominal pain in IBD (9). Moreover, the heterogeneity of pain profiles between individuals and balance with controlling the disease creates further challenges to pain management.

The sub-theme of cycles of IBD symptoms adds to the recent yet small body of literature in IBD on symptom clustering. In IBD fatigue research, patients with chronic fatigue have shown increased scores for pain intensity (20). This has parallels in other long-term conditions such as rheumatoid arthritis (RA) and multiple sclerosis (MS) (21, 22). In a qualitative study on MS-pain, Harrison and colleagues (22) identified unhelpful cycles of pain, fatigue and weight gain that came with avoidant techniques. These cycles may be explained by the exhausting nature of pain, or the impact that fatigue has on implementing strategies to manage pain (21). Alternatively, these may occur in parallel, as has been shown in RA longitudinal research (23). A recent longitudinal study in IBD examined symptom clustering and found that a third of its sample reported high symptom burden, which remained stable over 1 year (24). Importantly, the study showed that only 19% of participants who transitioned into remission status over this period showed reduced symptom burden. This is supported by findings from the current study, which demonstrated the ongoing experience of symptoms in remission and their collective impact. It is apparent that despite reaching clinical and endoscopic remission, IBD medical therapy does not always achieve symptom relief for patients (25). It is important to recognise the persistent and collective nature of symptom burden in IBD and address how symptoms can be targeted in self-management interventions.

There was divided opinion and approaches used for managing pain. Diet was often discussed in relation to pain in remission. Some used food-specific strategies in acute pain episodes such as herbal

teas, plain foods or exclusion of food groups. Diet in IBD is a complex and inconclusive area, with individual differences in gut microbiota seen to be a key influential factor (26). In this study, participants dietary approach was usually a result of learning from prior experience, however participants also recognised that food and symptoms were not always consistent. This added to a lack of understanding around the influence of diet on pain and frustration associated with an ongoing search for a solution. A recent study comparing dietary behaviour among IBD patients with and without pain showed that patients pain in quiescent disease or mild inflammation showed more negative views on their appetite and sense of taste, ate significantly fewer meals, lost weight more frequently and had a reduced time to satiety (27). Other research has demonstrated the discordant views among patients and clinicians regarding the role of diet in IBD, including differing opinions within different types of clinicians (28). Clearly a better understanding and unified approach to diet, pain and IBD is required.

A similarly divided opinion existed for the role of pain medication in IBD. Generally, use of pain medication was viewed negatively, be this due to apprehension over side effects or associated long-term risks with stronger pain medication. Opioid dependence is becoming an increasingly recognised issue in IBD, with prevalence rates rising in England (29) and the USA (30). Ample evidence now demonstrates the clinical characteristics and associated risks of long-term opioid use, including psychiatric diagnosis, hospitalisation and development of narcotic bowel syndrome (31, 32). Patient awareness of the risks associated with these approaches, as well as identification of at-risk individuals of chronic opioid use (33, 34), should be of concern to clinicians during discussion of pain management.

Despite varying opinions and approaches used among participants, the majority took a holistic approach to managing their pain and IBD. However, the need for more psychological support was voiced, as participants expressed the emotional toll and relentlessness of coping with their pain and other IBD symptoms on a daily basis. This need is well-supported in both qualitative and quantitative IBD research (35-39). Alongside a lack of addressing mental health issues, patients also generally felt

dissatisfied with the level to which pain specifically is addressed in consultations, with it frequently being buried underneath assessment of bowel patterns or aims towards remission targets. Assessment of pain in routine clinical practice is usually embedded within global rating measure of disease activity, such as the Harvey Bradshaw Index (40) or Simple Clinical Colitis Activity Index (41). This not only confines individual's rating of pain to the abdominal region but hinders a more comprehensive assessment of pain. The study's findings resonate with several studies demonstrating patient's need of pain being more adequately addressed and the discrepancy between clinician's and patients views on patient priorities (4, 42). Disentangling pain from other IBD symptoms appears a challenge both for patients and within clinical consultations.

This study demonstrated participant's resilience and stoic approach to pain. Resilience, defined as "effective functioning despite exposure to stressful circumstances and/or internal distress" (43, 44) is an increasing area of research in chronic illness and pain, and highlights the need to recognise protective factors which allow some individuals to function in the face of pain (45). Participants who appeared accepting of their pain conveyed the positive impact this had, such as having greater perceptions of control and daily functioning. This contrasted with other participants who conveyed frustration and hopelessness in their search for a solution. Similarly juxtaposing approaches have been demonstrated in musculoskeletal pain qualitative research, which identified fighting versus acceptance of pain as one of several 'adversarial struggles' for chronic pain patients (46, 47). In IBD research, greater disease acceptance has been associated with better adjustment outcomes, including social and emotional functioning (48). A better understanding of positive psychological processes in the context of IBD pain may have important implications for pain management interventions, and provide an explanation as to why some individuals may be at greater risk of psychological distress and chronic IBD pain.

Limitations of the study include the exclusion of non-English speakers and a predominant White-British cohort, limiting the transferability of findings to other cultures. However, the purposive sampling framework used aimed to include a balance of gender, IBD diagnosis, age and disease

duration. Findings can also only be drawn from one time point, and it is important to recognise processes of change over time which could be captured in more longitudinal research. Participants current disease activity was not measured at time of interview, thus limiting the extent to which their pain could be explained by inflammatory or disease-related processes. Findings were not returned to participants for feedback or validation. This is a controversial issue in qualitative research, as it is argued that 'member-checking' invites its own limitations and incongruences (49). Lastly, prior knowledge and understanding of chronic pain and psychological processes by the authors and interviewer may have resulted in bias in interviewing and analytical processes. However, the use of group meetings to moderate and critique codes and themes before arriving at the results aimed to negate this degree of bias.

Clinical implications of findings

The findings highlight the lack of a defined treatment pathway for patients with IBD experiencing pain. Consequently, participants rely on their personal set of strategies to self-manage their pain and associated IBD symptoms. Given the heterogeneity in pain and disease profiles, the task of reaching a definitive approach for pain management in IBD may be challenging. However, it is important that clinicians can offer evidence-based self-management techniques to patients and facilitate patient autonomy and confidence to cope with pain. As a result, further research is needed in this area of IBD. Results also reinforce the need for more robust and holistic assessment of pain in IBD, separately from global disease activity rating.

Participants expressed the need for better psychological support and assessment of pain in clinical practice. Psychological intervention may be a helpful adjuvant approach for patients experiencing pain and psychological distress. For example, techniques used in cognitive behavioural therapy (CBT) may help alleviate stress, anxiety and avoidant behaviours caused by and contributing to pain. Acceptance appeared to facilitate participant's ability to apply helpful strategies and has been a widely recognised mechanism in the chronic pain literature (50, 51). Acceptance and mindfulness are

key tools used in both in CBT and acceptance and commitment therapy (ACT). Positive psychological techniques, alongside reducing negative thoughts and behaviours, hold merit in pain management interventions and show increasingly promising evidence (52, 53).

Conclusions

Pain is a highly burdensome and poorly understood symptom of IBD. Both the experience and impact of pain interacts significantly with accompanying IBD symptoms. Consequently, it is difficult to effectively assess and treat pain, and have a clear understanding of its aetiology. Due to the heterogeneity in pain profiles and interaction with disease prognosis among patients, use of pain management strategies rely on patient learning from their own prior experiences, including use of short-term pragmatic strategies and long-term maintenance solutions. This group of individuals with IBD demonstrate a resilient approach, tolerating daily levels of pain despite searching for adequate solutions. It is important to support patients in their ability to self-manage and negate risk of emotional distress by facilitating understanding of their symptoms and good therapeutic communication.

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Table 1. Topic guide for IBD pain interviews

Question	Probes
Can you tell me about the pain you experience, in relation to your IBD?	<ul style="list-style-type: none"> • Do you experience pain in active disease and in remission? • Do you experience different types of pain? • How would you describe the pain sensations? And location? Same location or different? • What is the pattern of the pain, continuous or intermittent? • How does your pain impact you, daily? E.g. sleep, mood, social relations, work, physical activity
What other symptoms do you experience in relation to your IBD?	<ul style="list-style-type: none"> • How much does pain interfere in your daily functioning in comparison to these other symptoms? • Have you found that your pain is associated with any of your other symptoms? • What do you think is causing your pain, in active disease? And in remission? • What are your thoughts or concerns when you experience pain?
Can you tell me about some of the ways that you manage your pain?	<ul style="list-style-type: none"> • What strategies have you found helpful in reducing your pain levels? • What strategies have you found not helpful in reducing your pain levels? • How do these techniques help you? Physically/mentally? • Do you react similarly to different types of pain? Do you use the same techniques for different types of pain (if you experience different types of pain?) • Tell me about a typical day of yours when you are in pain, and when you are not in pain.
How do others around you react to your pain?	<ul style="list-style-type: none"> • To what extent do you have supportive friends and family that help you manage your symptoms? • To what extent do you disclose your pain to loved ones? • To what extent do you think others understand what you are experiencing?
What do you think could be done to help you with your pain?	<ul style="list-style-type: none"> • Are there particular areas in your life where you feel you need better support with regards to your pain? E.g. exercise, diet, medications, social activities, work • What would help you better manage your pain symptoms on a daily basis, or when you experience pain? • In an online treatment programme, what type of skills or information do you think would be most useful to have with regards to managing your pain? • Is there anything from healthcare professionals and treatment that you would like to help with your pain? • What could be addressed more in treatment for your pain?

Table 2. Details of interviewed participants

Participant	Gender F/M	Age	Diagnosis	Ethnicity	Disease Duration (yrs.)
1	F	36	UC	White – other	35
2	M	22	CD	White British	9
3	M	47	UC	White British	19
4	M	46	UC	White British	5
5	F	41	CD	White British	2
6	F	17	UC	Black or Black British African	1
7	F	55	UC	Mixed – White and Black African	38
8	F	31	CD	White British	6
9	M	20	UC	Asian or Asian British – Pakistani	2
10	F	34	CD	White British	22
11	M	37	UC	White British	17
12	F	23	UC	White Irish	3
13	F	39	UC	White British	5
14	F	36	CD	White British	7

Key: M – male, F = female, UC – ulcerative colitis, CD – Crohn’s disease

Table 3. Example quotes of sub-themes of ‘Attitudes’ - Tolerance and Acceptance

Tolerance	Acceptance
<i>“With having the children, I’ve had to find a way to cope. So if it’s passable, then I just grin and bear it” (10)</i>	<i>“You just have to embrace it is what it is. And try and find a way to make it fit into your life” (5)</i>
<i>“I’ve just got to like bite the bullet, you know, it’s quite uncomfortable” (3)</i>	<i>“I just tend to get on with it, at the moment. I try to, you know, to just accept it” (4)</i>
<i>“You have to get on with life. And you’re in agony” (10)</i>	<i>“Make friends with your pain, be aware of it, and almost have a communication with it” (7)</i>
<i>“It’s become part of me, which has been hard to get used to, but you’ve got used to have to deal with it” (7)</i>	<i>“It’s about building, you know, within, you kind of have to look into how your body is.” (5)</i>
<i>“I think, it’s just about willpower in the end. You’ve just got to keep going” (13)</i>	<i>I’m much better, oh my God, before, I would be like oh, a mess, a mess. I’d basically hide under the – but it isn’t, what good does that do you?” (7)</i>
<i>“Not being able to pull out of something, it just makes me have to cope” (1)</i>	<i>“I’m just like, “Oh stop feeling sorry for yourself, just get on with it. There are people around that don’t have legs. There are people around, you know, that have much worse stuff than you have, just stop it, deal with it” (7)</i>
<i>“Sometimes you don’t always want to pick yourself up. But you have to” (8)</i>	

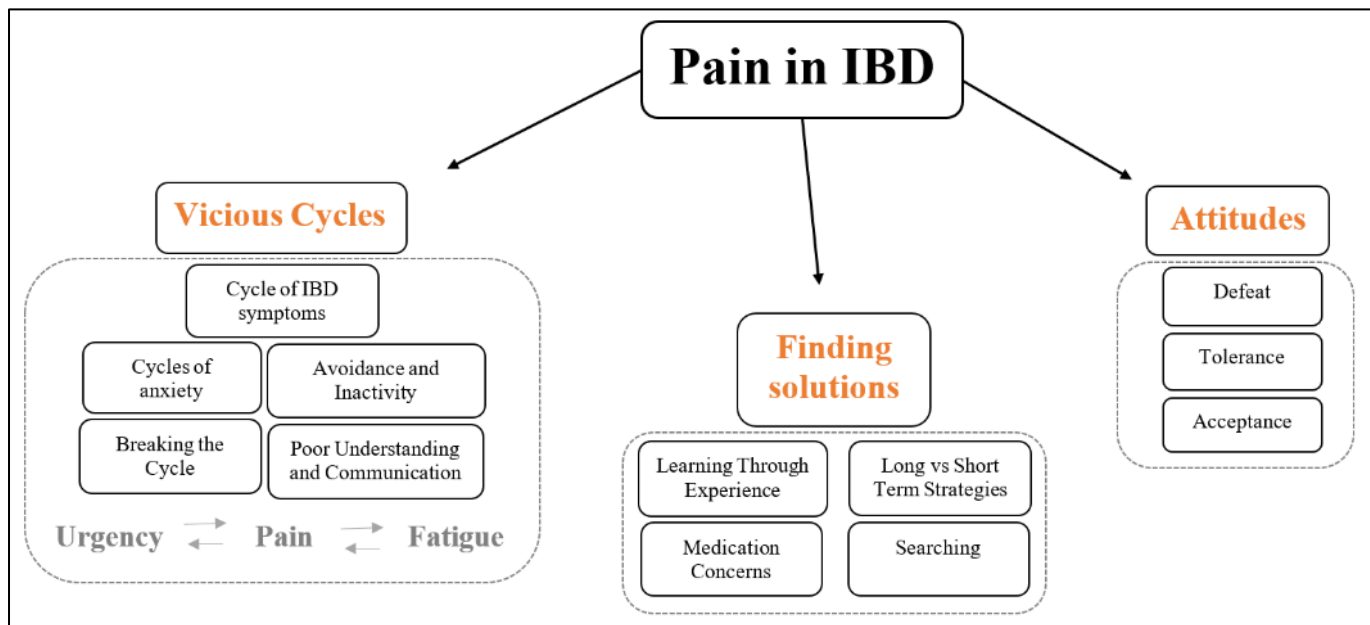


Figure 1. Thematic map of pain in IBD

